



NEWSLETTER



Information and Privacy Commissioner / Ontario

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Messages from the Assistant Commissioners

Privacy

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On September 17, 18 and 19, I attended the XII Annual Conference of Data Protection Commissioners hosted by France's Commission nationale de l'informatique et des libertés in Paris, France. Together with representatives from several countries including Canada, Germany, England, Denmark, Japan, United States, Australia and France, all with data protection (privacy) legislation, the conference explored timely and borderless privacy issues. Specifically, the three-day conference featured speakers who addressed the protection of medical data, medical research and genetics, and data protection developments in the world.

Representatives from Germany discussed the problems associated with using genetic analysis in the workplace, an interesting exchange considering their recent release, **Opportunities and Risks of Genetic Technology**, containing guidelines to control the threat to privacy posed by genetic analysis. At the conference, representatives from Great Britain discussed privacy protection with regard to medical data. As well, a speaker from France presented a paper on the use of medical data for research purposes.

Mr. Jacques O'Bready, President of Quebec's Commission d'accès à l'information, presented a paper, jointly developed by the Information and Privacy Commissioners of Canada, Ontario and Québec, which focused on medical records, particularly medical testing.

The subject is especially pertinent as the advent of new technology -- smart cards, screening tests, the mapping of human genetic structure -- coupled with rising concern over infection and disease is leading to widespread testing. Increasingly, protection of privacy is not being addressed by promoters of new testing techniques.

The paper explored the three jurisdictions' positions on AIDS-related testing, drug testing and genetic analysis. In

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Access

From September 12 - 15, I attended the 12th Annual Conference of COGEL (Council on Governmental Ethics Laws) hosted by the Alaska Public Offices Commission in Anchorage, Alaska. Founded in 1977, COGEL is a U.S.-based professional organization for agencies and individuals with responsibilities in the areas of government ethics, elections, campaign finance, lobby law regulation, and, as added two years ago, freedom of information.

This year's conference, which attracted 200 delegates from the United States, Europe and Canada, addressed topics ranging from review and enforcement of personal financial disclosure laws to the problems and solutions relating to providing on-line access to government records.

The latter was particularly interesting as on-line access to and electronic dissemination of government information has been hailed as one of the "issues of the '90s" in the freedom of information arena. Mitchell Pearlman, Executive Director of the Connecticut Freedom of Information Commission, Karen Boorman, Executive Director of the Alaska Public Offices Commission, Robert Shaw Jr., Program Manager, Information Security Support, IBM Corporation, and Richard Mauer, Investigative Reporter with the **Anchorage Daily News**, discussed the advantages and disadvantages of on-line access, as well as the capabilities of current technology. Generally, enthusiasm for the technology runs high, yet financial restraints often prevent its implementation. For example, lack of funds has thwarted panelist Karen Boorman's initiative to provide interested parties with on-line access to information collected on candidates running for political office in Alaska. It should be noted that some government bodies in the United States have bypassed the request process and are providing on-line access to certain classes of government records.

I spoke at two sessions at the conference. In my first presentation under the theme of "Legislative Updates", I gave dele-

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Privacy (cont'd)

summary, privacy advocates for Canada, Ontario and Quebec insist upon voluntary HIV/AIDS-related medical testing. Anonymous testing and the removal of existing mandatory nominal reporting requirements is strongly encouraged by the Information and Privacy Commissioner/Ontario as detailed in *HIV/AIDS: A Need for Privacy*. (See article on page 3.) At present, mandatory nominal reporting is required in Ontario, unlike Quebec where HIV/AIDS-related testing is conducted anonymously.

Privacy advocates for Canada, Ontario and Quebec also questioned the accuracy of current drug testing practices and genetic analysis techniques. They outlined their concerns relating to the dangers of using and depending on information obtained through these methods.

With the introduction of an integrated market in Europe in 1992, delegates were briefed on data protection and telecommunications throughout the European Community. Thereafter, Luxembourg presented a draft resolution on the subject. Delegates also learned about data protection developments in Japan, Denmark, Finland, Norway and Sweden.

I consider the XII Annual Conference of Data Protection Commissioners to have been a great success. Plans are underway for the XIII Annual Conference of Data Protection Commissioners, scheduled for the fall of 1991 in Strasbourg, France.

Ann Cavoukian, Ph.D.

Copies in English or French of **A Paper regarding Medical Records**, presented by Jacques O'Bready on behalf of the Information and Privacy Commissioners for Canada, Ontario and Quebec at the XII Annual Conference of Data Protection Commissioners in Paris, are available from the Information and Privacy Commissioner/Ontario.

Access (cont'd)

gates a brief history of freedom of information and privacy in Canada. Grouping jurisdictions with freedom of information legislation into those with investigative or adjudicative powers, I discussed some recent legislative and personnel changes, and finally focused on Ontario's experience. Following a review of the details surrounding the January 1, 1991 implementation of the *Municipal Freedom of Information and Privacy Act*, I shared the experiences of our Commission in dealing with the two issues of custody or control of a record (Order 120) and access to handwritten records (Order 194).

In the second session, together with representatives from freedom of information commissions and the media, the personal privacy aspect of access to public personnel records was addressed. The question: Where to draw the line?

In my remarks I referred to two situations that had arisen in Ontario, the first of which involved an access request for salaries of hospital officials. Former Commissioner Sidney Linden addressed this issue in Order 61 in which he decided that the release of the actual salaries of named officials or public servants in general would be an unjustified invasion of privacy. However, he concluded that salary ranges should be accessible to the public.

The second case concerned a request for personal information of the successful candidate in a job competition. Reviewed in Order 99, Commissioner Linden ordered Ontario's Human Rights Commission to disclose the requested personal information, namely the resumé of the successful candidate, two letters of personal recommendation and notes written by the interviewers. After considering the unique circumstances of the organization, and the need to submit its actions to public scrutiny, the Commissioner concluded that the public's right to know outweighed and justified the possible invasion of personal privacy.

As I informed delegates, the Commissioner's Office has considered how the disclosure of personal information of a public employee relates to the operations of the institution. Certainly public employees must be accountable to the public, but the provisions of the *Freedom of Information and Protection of Privacy Act* must also be considered.

COGEL's 12th Annual Conference featured interesting and insightful discussion on a variety of ethics-related issues, and was an unqualified success. COGEL's 13th Annual Conference will be held in the fall of 1991, on Hilton Head Island in South Carolina. Toronto will host delegates at COGEL's 14th Annual Conference in the fall of 1992, an event in which the Commissioner's Office looks forward to participating.

Tom Wright

HIV/AIDS: A Need for Privacy

Privacy and its protection has become a major sub-theme in any discussion of how society is to deal humanely with HIV/AIDS. The Office of the Information and Privacy Commissioner/Ontario has a mandate to consider privacy issues related to the *Freedom of Information and Protection of Privacy Act, 1987*, and an obligation to bring forward the issues relating to this sub-theme for examination. In this report, we are also presenting guidelines and recommendations for consideration.

It is the responsibility of the various provincial institutions which deal with sensitive personal information such as HIV/AIDS-related information to collect, use, retain and disclose this information conscientiously and cautiously. It is the responsibility of the Office of the Information and Privacy Commissioner/Ontario to ensure that institutions adhere to the principles of conscientious and cautious handling of such personal information as required by the *Freedom of Information and Protection of Privacy Act, 1987*.

This month, the Office of the Information and Privacy Commissioner/Ontario released **HIV/AIDS: A Need for Privacy**, its second initiative to address privacy concerns relating to HIV/AIDS. Specifically, **HIV/AIDS: A Need for Privacy** deals with the broader issues associated with HIV/AIDS, such as anonymous testing, mandatory reporting, contact tracing and other related issues. The first such initiative, **HIV/AIDS in the Workplace**, was released in December 1989. It recommended several privacy principles for employers and employees to follow when dealing with HIV/AIDS-related personal information.

HIV/AIDS: A Need for Privacy focuses directly on the privacy aspects of HIV testing and reporting. It is clearly difficult to balance the positive benefits and the potentially negative consequences of the collection, retention, use and disclosure of HIV/AIDS-related personal information. Testing procedures must be clearly designed to reassure all sectors of society, especially those engaging in high-risk activities, that being tested or providing HIV/AIDS-related personal information will not lead to disclosure of such information beyond those who absolutely need that information, such as one's physician. In seeking this balance, we believe that the negative consequences could be minimized if the government adopted a policy of anonymous testing and partner notification.

The Office of the Information and Privacy Commissioner/Ontario makes several recommendations in this report on privacy and anonymous HIV testing, non-nominal reporting and partner notification. (See box for details ter.)

We feel strongly that new policies and procedures must be developed to better address the sensitive balance between the need to control the spread of HIV infection and the need to secure individual privacy. There should be an explicit recognition of the need to maximize the confidentiality of HIV/AIDS-related information.

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Recommendations made in HIV/AIDS: A Need for Privacy

Recommendation 1

Anonymous testing for the presence of the HIV antibody should be available for persons who wish to be tested. The Health Protection and Promotion Act or legislation intended to replace it, should not require mandatory nominal reporting of HIV positive test results. Any obligation imposed by legislation to report nominal HIV/AIDS-related personal information should be removed, and legislation enacted to permit anonymous testing for HIV antibodies.

Recommendation 2

The physician who orders an HIV antibody test should be responsible for partner notification and counselling -- the primary objective being to facilitate voluntary partner notification by the affected individual. If the individual refuses to notify partners at risk, the physician should undertake to do this, with or without the assistance of the individual. The physician may elect to defer partner notification/counselling to a Medical Officer of Health, if he/she is unwilling or unable to perform this function.

Recommendation 3

If necessary, the Health Disciplines Act should be amended to include the concept of a physician's "duty to warn", enabling physicians to warn those at risk of transmission. Such a duty to warn should only be exercised if an individual infected with a communicable disease such as HIV, refuses to inform his/her partner of this fact and also refuses to give the physician permission to do so on his/her behalf.

Recommendation 4

There should be no mandatory testing for the presence of antibodies to HIV. This would not preclude, however, HIV testing of all donated blood, tissues, semen and embryos and universal testing as part of anonymous, unlinked seroprevalence surveys.



Book Review

Using Canadian Freedom of Information Legislation; A Public Interest Researcher's Experiences

By: Ken Rubin

Ken Rubin's *Using Canadian Freedom of Information Legislation; A Public Interest Researcher's Experiences* is an interesting self-publication from one of Canada's foremost access advocates.

Mr. Rubin has deftly compiled an assortment of newspaper and journal articles, as well as excerpts from the federal and Ontario Hansards, that focus on his own involvement in using access laws in several Canadian jurisdictions.

The contents of the publication cover articles on Mr. Rubin himself that have appeared in such magazines as *Saturday Night*. Also included are articles that provide advice on how to use access legislation, principally the federal law, as well as his assessments of the effectiveness of such legislation. He also has some interesting things to say about the Ontario and Manitoba access laws. Several articles deal with how parliamentarians and labour advocates can use these laws.

Perhaps the most interesting articles are those that have appeared in various newspapers, the information for which was supplied by Mr. Rubin through his use of the various freedom of information acts. Here Mr. Rubin lets "the cat out of the bag" to reveal that he was the "ghost" researcher for these stories.

The value of Mr. Rubin's publication lies in providing us with a glimpse of how access legislation is being used by the media and those individuals like Mr. Rubin who have made the most of Canada's freedom of information laws.

John Eichmanis

**(The book is available from Ken Rubin,
212 Third Avenue, Ottawa K1S 2K3)*

Upcoming Seminars and Conferences

November 27, 1990 in Toronto

Riley Information Services Inc. presents **Is Privacy Important to your Company Today? Canadian and International Developments**. For details, contact: Tom Riley, 633 Bay Street, Suite 2207, Toronto, Ontario M5G 2G4. Phone: (416) 593-7352 Fax: (416) 593-0249.

April 22 and 23, 1991 in Ottawa

CAPA (Canadian Access and Privacy Association) in conjunction with Riley Information Services Inc. presents **Access '91: Pursuing Practical Policies for the '90s**. For details, contact Tom Riley at the address or telephone number listed above.

HIV/AIDS: A Need for Privacy (cont'd)

These policies and procedures should contain a recognition that maximum confidentiality of information related to HIV/AIDS is an essential public health measure. In order to retain the full trust and confidence of persons at risk, the government has an interest both in ensuring that HIV/AIDS-related information is not improperly disclosed, and in having clear rules for the appropriate disclosure of such information. Our recommendations place the physician at the centre of the testing and partner notification processes.

Incorporated into this role for the physician is the "duty to warn" those at risk of transmission. We believe that our recommendations achieve the objective of drawing the circle tightly around those who will have access to HIV/AIDS-related personal information.

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